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Assistive Technology Needs, Functional Difficulties, and Services Utilization and Coordination of Children with Developmental Disabilities in the United States

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ABSTRACT

Assistive technology (AT) enhances the ability of individuals with disabilities to be fully engaged in activities at home, at school, and within their communities—especially for children with developmental disabilities (DD) with physical, sensory, learning, and/or communication impairments. The prevalence of children with DD in the United States has risen from 12.84% in 1997 to 15.04% in 2008. Thus, it is important to monitor the status of their AT needs, functional difficulties, services utilization, and coordination.

Using data from the 2009–2010 National Survey on Children with Special Health Care Needs (NS-CSHCN), we conducted bivariate and multivariate statistical analysis, which found that 90% or more of parents of both children with DD and other CSHCN reported that their child's AT needs were met for vision, hearing, mobility, communication, and durable medical equipment; furthermore, children with DD had lower odds of AT needs met for vision and hearing and increased odds for meeting AT needs in mobility and communication.

Our findings outline the current AT needs of children with DD nationally. Fulfilling these needs has the potential to engender positive lifelong effects on the child's disabilities, sense of independence, self-confidence, and productivity.

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assistive technology needs;
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Background

Assistive technology (AT) enhances the ability of individuals with disabilities to be more fully engaged in activities at home, at school, and within their communities (Berry & Ignash, 2003; Murchland & Parkyn, 2010; Salminen, Brandt, Samuelsson, Töytäri, & Malmivaara, 2009). The Assistive Technology Act of 2004 defined an AT device as any item, piece of equipment including durable medical equipment, or product system such as communication or mobility aids and devices that can enhance the functional abilities of individuals with disabilities (Assistive Technology Act of 2004, 2004). The intent of the AT Act is to promote public awareness of and to support the access to AT devices and services for individuals with all disabilities of across all ages. For children with disabilities age 0–21 years old, the Individuals with Disability Education Act (IDEA) mandated the consideration of AT interventions in their Individualized Education Plans (IEP; IDEA of 2004). However, children with disabilities and their parents continue to encounter challenges in AT awareness, AT advocacy, effective implementation of AT interventions in school systems, and in access to trained providers (Burne, Knafelc, Melonis, & Heyn, 2011; Copley & Ziviani, 2004).

Among children with special health care needs (CSHCN), children with developmental disabilities (DD) may have physical, learning, behavioral, and/or communication impairments that require personal assistance or special equipment in carrying out activities of daily living, and have profound impact on their psychosocial and educational development (Henderson, Skelton, & Rosenbaum, 2008; Newacheck et al., 1998). The federal

Maternal and Child Health Bureau (MCHB) defined CSHCN as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services beyond that required by children generally” (McPherson et al., 1998, p. 138). As a result, children with DD encounter barriers to full participation in school-related and social activities that are integral to their health and well-being (Arim, Findlay, & Kohen, 2012; Raghavendra, Virgo, Olsson, Connell, & Lane, 2011; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001).

Previous smaller scale studies have found that AT access for children with DD can lead to positive outcomes in education and independence (Edyburn, Higgins, & Boone, 2005). For example, students with autism spectrum disorder (ASD) were much more likely to partake in a school's general assessment with AT access (Barnard-Brak, Thompson, Wei, & Richman, 2014). In addition, AT provided through special education services in public school settings demonstrated significant impact on improvements toward IEP goals, post-secondary educational attainment, and independent living outcomes (Bouck, Maeda, & Flanagan, 2012; Watson, Ito, Smith, & Andersen, 2010). Furthermore, children with cerebral palsy gained a higher level of mobility independence with access to manual and powered wheelchairs at an early age (Rodby-Bousquet & Häggglund, 2010). Furthermore, larger national studies using data from 2005–2006 National Survey on Children with Special Health Care Needs (NS-CSHCN) found that children with neurologic conditions and disabilities have more unmet health care and service needs than CSHCN (Bitsko et al., 2009; Houtrow, Okumura, Hilton, & Rehm, 2011).

However, less is known about progress and status of AT needs, functional difficulties, and service utilization and coordination among children with DD nationally from more recent national survey data.

The prevalence of children with DD in the United States has risen from 12.84% in 1997 to 15.04% in 2008 (Boyle et al., 2011). However, the majority of the health services research has been focused on the prevalence, characteristics, unmet needs of CSHCN overall, or individual disability types such as ASD (Chiri & Warfield, 2012; Kogan et al., 2008; Strickland et al., 2011; van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004; Warfield & Gulley, 2006). To monitor the status of AT needs, functional difficulties, services utilization and coordination among children with DD nationally, we analyzed the nationally representative survey data from the 2009–2010 NS-CSHCN for the following study aims: (1) provide descriptive cross-sectional sociodemographic profile of children with DD in the United States and their AT needs, functional difficulties, service utilization and coordination; and (2) examine the association between having a DD and AT needs, functional difficulties, and service utilization and coordination.

Methods

Data source and sample design

The NS-CSHCN is a national, cross-sectional telephone survey conducted by the Centers for Disease Control and Prevention's (CDC) National Center on Health Statistics (NCHS) with funding from MCHB (van Dyck et al., 2002). The NS-CSHCN was first administered in 2001 with the goal of generating national prevalence estimates for CSHCN between the ages of 0–17 years old, and to further understand their family demographic and socioeconomic characteristics, access to care, satisfaction with care, and family impact of care (van Dyck et al., 2004). Subsequent surveys were carried out in 2005–2006 and 2009–2010. Interviews were conducted with a parent or guardian who had comprehensive knowledge of their child. The 2009–2010 NS-CSHCN data collection commenced in July 2009 and concluded in March 2011. The total sample for the 2009–2010 NS-CSHCN was comprised of 40,242 subjects. The interview completion rates for landline, cell phone, and combined sample were 83.6%, 76.6%, and 80.8%, respectively (CDC, 2011; Bramlett et al., 2014).

NCHS utilized the State and Local Area Integrated Telephone Survey (SLAITS) technology for sampling and survey administration. The sampling frame is the same as CDC's National Immunization Study (Blumberg et al., 2008; Child and Adolescent Health Measurement Initiative, 2012). NS-CSHCN has a complex sample design, with stratification by state and sample type, and with clustering of children within households. The NS-CSHCN sample design is comprised of two sample types: the state-based main sample and the national referent sample. In the main sample, the interviewer screened all children in the household for special needs and carried out the interview only if a CSHCN was present in the household. The referent sample of children without special health care needs was used to generate the national and state estimates for CSHCN. The telephone numbers of the

NS-CSHCN main and referent samples were generated from random digit dialing (RDD) through the National Immunization Survey (NIS) screening process. If the NIS samples were insufficient to attain the desired number of completed interviews in the main sample, then additional telephone numbers were randomly selected to obtain the NS-CSHCN targets. The survey was administered in English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean.

Variables

The independent variable of interest was children with DD. The 2009–2010 NS-CSHCN asked parents about 20 specific conditions. Children with DD were identified by positive parental response to the child having the specific conditions of intellectual disability or mental retardation, ASD, cerebral palsy, developmental delay, Down syndrome, or muscular dystrophy.

The dependent variables of interest explored the following three overarching topics: (1) AT needs met; (2) functional difficulties; and (3) services utilization and coordination. We examined AT needs met in vision, hearing, mobility, communication, and durable medical equipment. Parents/guardians were asked to respond yes/no to the following five questions in the NS-CSHCN related to AT needs: (1) Did [Subject Child (S.C.)] receive all the eyeglasses or vision care that [he/she] needed?; (2) Did [S.C.] receive all the hearing aids or hearing care that [he/she] needed?; (3) Did [S.C.] receive all the mobility aids or devices that [he/she] needed?; (4) Did [S.C.] receive all the communication aids or devices that [he/she] needed?; and (5) Did [S.C.] receive all the durable medical equipment that [he/she] needed?

With regards to functional difficulties, we selected three composite measures from the NS-CSHCN that examined parental report of multiple functional difficulties among CSHCN: (1) difficulties in one or more bodily functions such as respiratory problems, swallowing or metabolism, blood circulation, repeated or chronic physical pain, seeing even with corrective lens, and hearing even with hearing devices; (2) difficulties in activities or participation such as self-care, moving around, and limited hand use; and (3) difficulties in emotional or behavioral factors such as anxiety or depression, behavior problems (e.g., acting out, fighting, bullying, or arguing), and friendships. Finally, services utilization and coordination looked at parental responses (yes/no) to the following: (1) Does the child receive special education services; (2) Does the child need or use more medical care or educational service than their peers; and (3) Do the medical providers of the child need to coordinate and communicate with educational, vocational, or rehabilitation programs?

Sociodemographic covariates included gender (male and female), race/ethnicity (Hispanic, non-Hispanic White, non-Hispanic Black, and other), age groups (0–5 years old, 6–11 years old, and 12–17 years old), family structure (two-parent family, mother only, and other), household poverty level (below 100%, 100–199%, 200–399%, and 400% or more of Federal Poverty Level [FPL] for family size), and insurance type (private, public, both public and private, and uninsured). Covariates have been included in our model based upon previous research on disparities in AT usage (Kaye, Yeager, & Reed, 2008).

Statistical analysis

We conducted bivariate analysis to understand the sociodemographic profile of children with DD and CSHCN. In addition, we examined the relationship between child with DD and AT needs, functional difficulties, services utilization and coordination of children with DD and CSHCN. Chi-squared test was used to assess the statistical significance of the variables. We utilized the multivariate logistic regression analysis to investigate the association between having a child with DD and AT needs, functional difficulties, and special education service and coordination. Adjusted odds ratios (aOR) and 95% confidence intervals (CI) were computed by using the exponential function of the regression beta coefficients and standard errors while controlling for aforementioned individual-level socio-demographic covariates (Szumilas, 2010). Statistical Analysis System (SAS) version 9.3 survey procedure was used to carry out the analysis (SAS Institute, 2011). The public use file (PUF) of the 2009–2010 NS-CSHCN contained the child interview weights, which allowed for the generation unbiased estimates of the U.S. population while taking into account the state variable as strata and the household ID (Variable: IDNUMR) as the primary sampling unit (PSU) for variance estimation. We used the Taylor Series Linearization variance estimation method to estimate the sampling error for NS-CSHCN complex sample design (Rust, 1985).

Institution review board approval was waived exempt by the institution review board of the University of Maryland, College Park.

Results

The final analytic samples of children with DD and other CSHCN in the 2009–2010 NS-CSHCN were $N = 15,576$ and $N = 24,537$, respectively. Table 1 contains the socio-demographic characteristics of children with DD and other CSHCN. The proportion of males among children with DD (67.8%) was higher than among other CSHCN (53.8%). The race/ethnicity distribution was predominantly non-Hispanic White for both children with DD and other CSHCN at 62.1% and 57.4%, respectively. Among children between the age of 0–5 years, the proportion of other CSHCN 0–5 years old (26.6%) was greater than children with DD (12.0%). Over half of both children with DD (62.0%) and other CSHCN (69.3%) resided in two-parent family structures. The distribution among household poverty level indicated that 23.8% of children with DD and 29.7% of other CSHCN lived in household at or above 400% of FPL. Finally, 43.6% of children with DD and 58.1% of other CSHCN had private insurance. A larger percentage of children with DD (42.2%) received public insurance when compared with other CSHCN (31.7%). The chi-square test for all of the socio-demographic characteristics demonstrated statistically significant differences between children with DD and other CSHCN.

Table 2 compares the AT needs, functional difficulties, and service utilization and coordination between children with DD and other CSHCN. Among children with DD, the proportion of AT needs met were as follows: (1) vision need met was 97.1%; (2) hearing needs met was 99.1%; (3) mobility needs met was 96.8%; (4) communication needs met was 96.0%; and (5) durable

Table 1. Descriptive demographic characteristics of children with DD and other CSHCN in the United States.

Characteristics (weighted %)	Children with DD (n = 15,576)		Other CSHCN (n = 24,537)		Chi-square (p-value)
	SE	SE	SE	SE	
Gender					<0.0001
Male	67.8	0.69	53.8	0.59	
Female	32.2	0.69	46.2	0.59	
Race/ethnicity					<0.0001
Hispanic	15.3	0.62	17.7	0.52	
Non-Hispanic White	62.1	0.76	57.4	0.60	
Non-Hispanic Black	14.8	0.60	17.0	0.48	
Other	7.9	0.42	7.8	0.31	
Age					<0.0001
0–5 years old	12.0	0.51	26.6	0.53	
6–11 years old	43.1	0.73	35.7	0.56	
12–17 years old	44.9	0.72	37.7	0.57	
Family structure					<0.0001
Two-parent family	62.0	0.75	69.3	0.57	
Single family	27.9	0.72	24.4	0.54	
Other	10.2	0.46	6.3	0.29	
Household poverty level					<0.0001
<100%	25.2	0.65	20.3	0.51	
100–199%	23.6	0.66	20.7	0.50	
200–399%	27.4	0.64	29.3	0.52	
400+%	23.8	0.58	29.7	0.51	
Insurance type					<0.0001
Private insurance ONLY	43.6	0.72	58.1	0.60	
Public insurance ONLY	42.2	0.76	31.7	0.58	
Both public and private	10.9	0.50	6.4	0.29	
Uninsured	3.3	0.28	3.8	0.28	

Note. Source: 2009–2010 National Survey of CSHCN.

Table 2. Comparison of AT needs, functional difficulties, services utilization and coordination of children with DD and other CSHCN in the United States.

Weighted %	Children with DD (n = 15,576)		Other CSHCN (n = 24,537)		Chi-square (p-value)
AT needs					
Vision needs met	97.1	0.25	98.2	0.15	<0.01
Hearing needs met	99.1	0.14	99.6	0.10	<0.01
Mobility needs met	96.8	0.27	89.6	0.39	<0.0001
Communication needs met	96.0	0.30	89.5	0.39	<0.0001
Durable medical needs met	99.3	0.10	99.5	0.08	0.21
Functional difficulties					
Difficulty with one or more body functions	61.3	0.70	73.9	0.51	<0.0001
Difficulty with one or more activities or participation	93.6	0.37	38.9	0.58	<0.0001
Difficulty with one or more emotional or behavioral factors	81.5	0.55	41.5	0.59	<0.0001
Services utilization and coordination					
Child receives special educational services	53.0	0.73	12.8	0.39	<0.0001
Child needs or uses more medical care, mental health, or educational services than is usual for their peers	64.3	0.71	35.0	0.57	<0.0001
Doctors or other clinicians need to communicate with school, early intervention program, child care providers, vocational education, or rehabilitation program	44.9	0.73	20.3	0.48	<0.0001

Note. Source: 2009–2010 National Survey of Children with Special Health Care Needs.

medical needs met was 99.3%. For other CSHCN, the proportion of AT needs met were as follows: (1) vision need met was 98.2%; (2) hearing needs met was 99.6%; (3) mobility needs met was 89.6%; (4) communication needs met was 89.5%; and (5) durable medical needs met was 99.5%.

With respect to functional difficulties, other CSHCN (73.9%) had a higher percentage of difficulty with one or more bodily function than children with DD (61.3%). However, children with DD had a higher proportion of difficulty with one or more activities or participation (93.6% versus 38.9%) and emotional or behavioral factors (81.5% versus 41.5%) than other CSHCN. With respect to service utilization, 53.0% of children with DD received special education services as compared to 12.8% of other CSHCN. Over 60% of parents of children with DD reported that their child needed or used more medical care, mental health, or educational services than is usual for their peers, whereas only 35% of parents of other CSHCN indicated as such. When parents were asked if doctors or other clinicians needed to communicate with school, early intervention program, child care providers, vocational or rehabilitation program, nearly 45% of parents of children with DD responded affirmatively while only 20% of parents of other CSHCN did.

Table 3 presents the aOR from the multivariate logistic regression analysis, where the model convergence criterion was satisfied. Children with DD had lower odds of AT needs met for vision (aOR = 0.63, 95%CI = 0.49, 0.83) and hearing (aOR = 0.44, 95%CI = 0.26, 0.75). Conversely, children with DD were at increased odds for meeting AT needs in mobility (aOR = 1.97, 95%CI = 1.58, 2.46) and communication (aOR = 1.54, 95%CI = 1.25, 1.90). The aOR for durable medical equipment (aOR = 0.79, 95%CI = 0.49, 1.28) was not statistically significant. While children with DD had lower odds of having difficulty with one or more bodily functions (aOR = 0.79, 95%CI = 0.49, 1.28), they were at higher odds of having difficulty with one or more activities or participation (aOR = 23.07, 95%CI = 20.04, 26.56), and with one or more emotional or behavioral factors (aOR = 5.52, 95%CI = 5.04, 6.06). For service utilization and coordination, children with DD had increased odds for receiving special education services (aOR = 7.21, 95%CI = 6.56, 7.92), needing or using more medical care, mental health, or educational services than is usual for their peers (aOR = 3.34,

95%CI = 3.08, 3.63), and doctors or other clinicians need to communicate with school, early intervention program, child care provider, vocational education, or rehabilitation program (aOR = 5.52, 95%CI = 5.04, 6.06).

Discussion

Children with DD were more likely to be male, non-Hispanic White, have public insurance, and older when compared to CSHCN. Findings from the multivariate analysis model demonstrated that children with DD had higher odds of having their mobility and communication needs met. This is positive news since mobility aids including manual and powered wheelchairs used at an early age may assist the child in the attainment of a higher level of mobility independence (Livingstone & Paleg, 2014; Rodby-Bousquet & Hägglund, 2010). Furthermore, children with DD who have significant speech impairments can greatly improve their communication with family members, teachers, and peers through the provision of supports of high quality augmentative and alternative communication interventions (Ogletree, Bruce, Finch, Fahey, & McLean, 2011; Reichle & Drager, 2010; van der Meer, Sutherland, O'Reilly, Lancioni, & Sigafoos, 2012). The finding on communication needs is similar to the increase in communication technology use reported from a nationwide survey of family members of individuals with intellectual disability and DD conducted through self-advocacy groups: the Arc of the US, and American Association on Intellectual and Developmental Disabilities (Palmer, Wehmeyer, Davies, & Stock, 2012). This may be attributed to the higher percentage of children with DD with public insurance compared with CSHCN, which has been found to increase the likelihood in use of services than children with private or no insurance for services to address augmentative communication and mobility needs (Benedict, 2006). This finding suggests potential success in public insurance coverage of communication and mobility assistive technologies.

However, our study found that children with DD were at lower odds for meeting their vision and hearing needs. Lack of visual correction treatment could negatively impact learning and motor skills development of children with DD (Bachman, Bachman, Franzel, & Marcus, 1994; Reimer, Cox, Nijhuis-Van, & Boonstra, 2011). Similarly, children experiencing learning difficulties have been shown to have a higher incidence of hearing loss than typical learners (Flexer, Millin, & Brown, 1990). This may be attributed to the lower percentage of children with DD identified between the age of 0–5 as compared with CSHCN due to the challenges in early detection of developmental delay and availability of universal early vision and hearing screening programs (Good, 2007; Yoshinaga-Itano, 2003). Thus, continuous and periodic vision and hearing screening and treatment to address vision and hearing AT needs for children with DD are critical.

With regards to functional difficulties, children with DD are at much greater odds of having difficulty with activities and participation as well as emotional or behavioral factors. Although our study found that they had much higher odds of receiving special education services and care coordination between clinical and educational providers as their other CSHCN peers, they continue to require much support.

Table 3. aOR for AT needs, services utilization and coordination of children with DD in the United States.

AT needs	aOR	95% CI
Vision needs met	0.63	(0.49, 0.83)
Hearing needs met	0.44	(0.26, 0.75)
Mobility needs met	1.97	(1.58, 2.46)
Communication needs met	1.54	(1.25, 1.90)
Durable medical needs met	0.79	(0.49, 1.28)
Functional difficulties		
Difficulty with one or more body functions	0.52	(0.48, 0.57)
Difficulty with one or more activities or participation	23.07	(20.04, 26.56)
Difficulty with one or more emotional or behavioral factors	5.52	(5.04, 6.06)
Services utilization and coordination		
Child receives special educational services	7.21	(6.56, 7.92)
Child needs or uses more medical care, mental health, or educational services than is usual for their peers	3.34	(3.08, 3.63)
Doctors or other clinicians need to communicate with school, early intervention program, child care providers, vocational education, or rehabilitation program	3.04	(2.79, 3.32)

Note. Source: 2009–2010 National Survey of Children with Special Health Care Needs. Reference group = other CSHCN. Multivariate model controlled for child gender, age, race, poverty level, family structure, and insurance status.

The juxtaposition of AT needs met for children with DD and receipt of special education services is a surprising finding in contrast to reported parental unhappiness and frustration toward the services provided by the school to address their child's special education needs (Mueller, Singer, & Draper, 2008; Ryndak, Downing, Morrison, & Williams, 1996; Spann, Kohler, & Soenksen, 2003). Globally, research indicates that the frequency of AT use at home and in school are dependent upon effective engagement of children with DD, parents, and teachers; without such engagement, low level of parental satisfaction toward AT services from access, follow-up, maintenance, and coordination will persist (Desideri et al., 2014; Huang, Sugden, & Beveridge, 2009a, 2009b; Raghavendra, Olsson, Sampson, McInerney, & Connell, 2012).

For children with DD, meeting their AT needs is critically important in enabling them to increase participation in activities at home and at school. As children with DD transition into adulthood, interventions addressing activity limitations and increasing postsecondary education attendance may increase the likelihood for the acquisition of adult social roles and mitigate risks for poor health and quality of life (Rurangirwa, Van Naarden Braun, Schendel, & Yeargin-Allsopp, 2006; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). Fulfilling the AT needs of a child with DD has the potential to engender positive lifelong effects on their disabilities, sense of independence, self-confidence, and productivity (Carpe, Harder, Tam, & Reid, 2010).

There are several limitations to this study. First of all, the cross-sectional design of 2009–2010 NS-CSHCN does not allow for causal inference. Second, the AT needs were reported by parents or guardians and not from the child's point of view. Parents may rate the AT to have a moderate to very large effect on the child's activities of daily living (ADL) (Ostensj , Carlberg, & V llestad, 2005). Therefore, the degree to which AT needs have been met and the difficulties in ADL are both more reflective of the care giver's perspective and may not be congruent with the child's perceptions. Third, six specific conditions were used to identify children with DD, which differed from other broader definitions of DD that more closely resembled the CSHCN definition. Fourth, the survey was conducted in English, Spanish, and four Asian languages, with the screener being in English or Spanish. This may bias the non-English respondents toward those who are more educated and fluent in English, resulting in a likely underestimate of risk for the Other, Non-Hispanic populations in the United States. Finally, potential selection bias in respondent participation may arise from respondents' willingness and availability to participate in a telephone survey.

Conclusion

The findings of this article outline the current AT needs as well as the functional difficulties of children with DD nationally. AT may enhance the ability of children with DD to actively participate and perform activities of daily living. They and their families could greatly benefit from the positive impact of having AT devices effectively integrated into their educational, social, and family life (Hemmingsson, Lidstr m, & Nyg rd, 2009; Nicolson, Moir, & Millstead, 2012). Future research is needed to continue monitoring the status of AT needs for this population.

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